Statement
of the
Home Health Services and Staffing Association
and the
American Psychoanalytic Association
presented by
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Mr. Chairman and Members of the Committee, thank you for the opportunity to present testimony today on behalf of the American Psychoanalytic Association (the "American") and the Home Health Services and Staffing Association ("HHSSA") with respect to patient care concerns arising from the Health Care Financing Administration's attempted implementation of the "Outcome and Assessment Information Set" or "OASIS".

At the outset, let me make absolutely clear that the American and HHSSA support legitimate and effective efforts to improve access to quality health care. It is for that very reason that we have serious concerns about the manner in which HCFA has sought to implement OASIS. OASIS implementation was suspended by HCFA on April 27, but in the two months that the data collection requirement was in effect, we found that it was acting as a barrier to quality health care services rather than enhancing access to quality care.

The two-month experience with OASIS offers an excellent example of what happens when identifiable patient data is collected without adequate payment and privacy protections. Specifically, we have found that:

- patients will refuse to provide certain sensitive medical information in an identifiable form even if it means that the services cannot be provided;
- the caregivers will "make up" the data in order to avoid terminating medically necessary services; and
- funds must be diverted from caring for the sickest, most costly patients to pay for the significant additional administrative costs.

Thus, a poorly planned and implemented data collection effort reduces or eliminates access to quality health care and produces corrupted data which leads to poor health planning and policy.

The Status of OASIS

Effective February 24, 1999, HCFA began requiring home health agencies to collect OASIS data on **all** patients, both Medicare and private pay, as a condition of participation in the Medicare program. 64 Fed. Reg. 3764 (January 25, 1999). The OASIS data collection instrument contained more than 450 data elements and had to be collected from the patients (1) upon admission, (2) upon discharge, (3) after any 48-hour hospitalization, and (4) every 60 days. 64 Fed. Reg. at 3784.

The data to be collected included the following information related to the patient's mental health, family situation and financial information.

Mental health information

The OASIS data includes extremely sensitive mental health information, including whether the patient:

- is in a "depressed mood (e.g., feeling sad, tearful)";
- has a "sense of failure or self reproach";
- has a feeling of "hopelessness";
- has "recurrent thoughts of death"; and
- has "thoughts of suicide". (62 Fed. Reg. 11052)

Family information

Other invasive questions include whether the patient lives:

- alone;
- with their spouse or a "significant other";
- with another family member;
- with paid help; or
- with someone else. (62 Fed. Reg. 11048)

Financial information

The patients must also disclose certain financial information including:

- whether they are unable to afford medical expenses that are not covered by Medicare;
- whether they are unable to afford to pay their rent or utility bills;
- whether they are unable to afford food;
- whether they own or rent their residence or if it is owned by a "couple" or "significant other"; and
- whether a family member owns their residence. (62 Fed. Reg. 11046, 11048)

This information was to be collected and reported to the state and federal governments in a fully identifiable form that included the patient's name, "ID number", Medicare number, state of residence, zip code and birth date. 62 Fed. Reg.11045. **All** of the information was to be collected on **every** patient regardless of whether the information was necessary for that patient's diagnosis and treatment. It was to remain on file with state and federal officials for at least three years. The regulations did not provide for notice to the patients or for a process to obtain their consent.

We raised the following legal and policy defects in the OASIS regulations in meetings with HCFA, members of Congress and the White House:

1. There is no indication of how HCFA plans to comply with the Privacy Act, 5 U.S.C. 552a. For example, the regulations do not indicate how HCFA plans to inform "each individual it asks to supply information" of (a) the authority for the requirement, (b) the principal purposes to which the information will be put, (c) the routine uses that will be made of the information, and (d) the effect on the individual of not providing the information.

2. The OASIS regulations would appear to violate several provisions of the Paperwork Reduction Act because:

- they authorize HCFA to "conduct or sponsor the collection of information" in advance of taking action to "reduce to the extent practicable and appropriate the burden on persons who will provide information to the agency"; and

- the information collection, as currently designed, is not "necessary for the proper performance of the functions of the agency".

44 U.S.C. secs. 3507(a) and 3508.

3. The OASIS regulations are in conflict with the rationale and the holding by the Supreme Court in Jaffee v. Redmond, 518 U.S. 1 (1996), which found that effective psychotherapy or counseling by a medical social worker cannot be performed unless the patient can have the "trust and confidence" that disclosures to a care giver will not be communicated further.

4. The OASIS regulations are in conflict with the laws of all 50 states and the District of Columbia which offer a psychotherapy privilege. See Jaffee v. Redmond.

5. The OASIS regulations are in conflict with the opinion rendered by HCFA on March 22, 1999, that the federal government may not gain access to the mental health records of non-Medicare patients because, "[f]irmly rooted in state case law, and established in federal law by the U.S. Supreme Court in Jaffee v. Redmond, 518 U.S. 1 (1996), the psychotherapist-patient privilege protects 'confidential communications between a licensed psychotherapist [or licensed social worker in the course of psychotherapy] and her patients in the course of diagnosis or treatment'. "

6. The OASIS regulations are in conflict with the representation, which the President made to mental health consumers in 1995 where he stated that he "supports the right of patients to receive [mental health] services without being compelled to disclose clinical records to. . . the government." See letter from President Clinton (July 31, 1995).

7. The OASIS regulations are in conflict with the recommendations for medical information privacy standards issued by Secretary of Health and Human Services, Donna Shalala on September 11, 1997.

8. Contrary to HCFA's assertions, many patients resisted providing the more than 450 data items, and home health agencies found that it imposed significant additional costs and burdens on staff. See "Case-mix Adjustment for a National Home Health Prospective Payment System", Abt Associates Inc., p. viii (December 1998).

9. In the final rule, HCFA does not explain why it is necessary to collect and report detailed personal information from non-Medicare patients. In fact, HCFA officials have informed us that they do not plan to use the data from non-Medicare patients in developing the case mix adjuster for the home health prospective payment system.

10. In the final rule, HCFA asserts that the OASIS information will allow the Secretary to assure that the conditions of participation are "adequate to protect the health and safety of individuals under the care of a home health agency." 64 Fed. Reg. 3764. The rule, however, sets forth no finding or data to show that the conditions of participation which have been in effect under Medicare for 35 years have been inadequate to protect the health and safety of individuals treated by home health agencies. Nor is any evidence cited to show that the quality of home health services is deficient in any way.

11. The OASIS regulations will impose a devastating financial burden on the home health industry, which was hit in fiscal 1998 with the largest percentage cut in reimbursement of any service in the history of the Medicare program (-15% growth rate according to recent CBO estimates).

In addition to the above concerns raised by health care providers, consumer groups, and patient advocacy organizations, several members of Congress also expressed concerns about HCFA's implementation of OASIS. Furthermore, several articles appeared in major newspapers around the country including:

1. "U.S. to Start Gathering Patient Data: Care Survey Draws Privacy Objections", The Washington Post, A1,March 11, 1999;

2. "U.S. to Amass More Data on Patients", The Los Angeles Times, March 11, 1999;

3. "More Data to Be Sought on Home Care", The New York Times, March 11, 1999;

4. "Data Sought on Home Care", The Boston Globe, A3, March 11, 1999;

5. "Home Health: HCFA to Start Gathering Personal Data", American Health Line, March 11, 1999;

6. "Under Fire, U.S. Amends Plan to Collect Health Care Data", The Washington Post, A5, April 1, 1999; and

7. "U.S. Puts off Collecting Medical Data", The Washington Post, A10, April 11, 1999.

In addition, both the American Civil Liberties Union (ACLU) and the Heritage Foundation strongly criticized the data collection effort. See "Home Nurses are Compelled To Do What Police Are Not Permitted To Do", The ACLU Massachusetts Medical Privacy Forum, and "HCFA's Latest Assault on Patient Privacy", The Heritage Foundation Executive Memorandum, March 22, 1999.

Finally, HCFA issued a notice dated April 27, 1999 announcing that they were delaying the "mandatory collection, use, encoding and transmission of OASIS" but only until clearances are obtained under the Paperwork Reduction Act.

HCFA's implementation of OASIS reduces access to quality home health services both because of the failure to protect patient privacy and because of the additional, uncompensated burden on home health agencies.

Privacy concerns

The American has been concerned for some years that access to effective psychotherapy will be eliminated unless the patient is permitted to communicate in private with a therapist. The United States Supreme Court reached a similar conclusion in the 1996 decision in Jaffee v. Redmond, in which it reviewed federal and state laws as well as canons of medical ethics and found that effective counseling by a medical social worker depends upon the patient having the trust and confidence that disclosures made to the social worker will not be further disclosed. 116 S.Ct. 1928.

Based on that finding, the Court recognized a "patient-therapist privilege" under federal law which, like the attorney-client privilege, cannot be waived without uncoerced patient consent. Accordingly, OASIS compels the routine disclosure of precisely the kind of information which the federal and state governments would be precluded from obtaining even under a court order in litigation. HCFA appears to agree since it issued an opinion on March 22 stating that the protection of such communications from disclosure is "firmly rooted" in both federal and state common law.

Thus, patients who agreed to provide the OASIS data were likely to cease making the kinds of disclosures that are essential for effective psychotherapy, including counseling by medical social workers.

HCFA officials also informed us that patients who refused to provide the information would have to have their services terminated. Accordingly, OASIS would eliminate access to services from Medicare certified home health agencies for these patients.

HCFA officials also informed us as recently as February 25 that during the collection of OASIS data in a 90-agency pilot project, "not a single patient objected to the collection of the data." A December 1998 interim report on the pilot project by the HCFA contractor, however, notes that one of the most "common implementation issues" was "gaining patient cooperation". The report states the following:

Sometimes it is not the staff who resists the OASIS form but the patients. Several patients tired of the long assessment quickly and refused to answer any remaining questions. Some patients were also reluctant to answer background questions, such as finances, schooling, etc.

See "Case-Mix Adjustment for a National Home Health Prospective Payment System", First Interim Report, Abt. Associates Inc., p. viii.

Feedback from home health agencies that tried to collect the OASIS data between February 25 and April 27 showed that many patients refused to furnish the information and that the caregivers simply supplied the responses that were necessary to preserve access to the services. This scenario poses a significant threat to the reliability of the data that HCFA intends to use to develop a prospective payment system. Accurate data is important, otherwise the quality of care will be further eroded by an inaccurate prospective payment reimbursement system.

In addition, home health agencies have found that the OASIS requirements are intrusive and threatening and restrict the relationship building activities so necessary to effective care planning, intervention and treatment. Patients become "guarded" and tend not to share their feelings and needs for fear of further intrusion and loss of privacy.

This experience is similar to that observed in a recent survey by the California HealthCare Foundation which noted that increasingly patients and caregivers are withholding or distorting clinical data in order to protect the privacy of sensitive medical information. According to a recent editorial discussing this survey, "privacy of medical records is not only a moral priority but a medical necessity." See "Medical Privacy Cannot Wait", The Los Angeles Times, May 10, 1999.

Diversion of funds to administrative costs

HCFA also seems to grossly underestimate the operational and financial burden that OASIS imposes on home health agencies that participate in the Medicare program. In the preamble to the final regulation, HCFA states that, "after the initial learning curve, OASIS data collection on an ongoing basis poses no additional burden above an HHA's routine patient assessment." 64 Fed. Reg. 3782. It defies belief that a 30-foot form with 450 pieces of information to collect, computerize and report would not pose a significant burden for patients and home health agencies.

In fact, that is precisely what the HCFA contractor administering the pilot program found. Two other "common implementation issues" noted by the contractor were:

1. "Incorporating the OASIS+ items into day to day operations was a major challenge for many HHAs."

2. "Finding the time for the OASIS+ assessment was an important staff concern. The range of additional time reported to complete an initial OASIS+ ranged from a low of 20 minutes to a high of 60 minutes."

See Abt Interim Report at viii.

Further, HCFA concludes that Medicare certified agencies will incur a one time "start up cost" for collecting OASIS data of $33 million in fiscal years 1999 and 2000 as well as start up costs of $11.4 million for data reporting. 64 Fed. Reg. 3760, 3782. HHAs will incur additional ongoing costs of data reporting of $22 million per year or $110 million over the next five years. 64 Fed. Reg. 3760. HCFA also estimates that 70% of home health agencies will receive no Medicare reimbursement for these additional costs because they are at or above their per beneficiary limit under the interim payment system. 64 Fed. Reg. 3776.

Information released by the Congressional Budget Office on March 12, 1999 shows that Medicare spending on home health services declined an incredible 15% in fiscal year 1998 alone. Accordingly, many home health agencies no longer have the funds or staff to implement OASIS. In addition, the funding and resources necessary to implement OASIS will be diverted from direct patient care.

Home health agencies that participate in Medicare will be placed at a further disadvantage because they will be forced to incur unreimburseable costs that non-Medicare agencies will not have to incur. Non-Medicare patients will find it more desirable to be treated by agencies that do not participate in Medicare because they will not have to relinquish their medical privacy to receive services from such agencies.

This problem will become much worse by October 1, 2000 when Medicare reimbursement to certified agencies is due to be reduced another 15% under section 4601(e) of BBA '97.

Conclusion

We do not oppose the implementation of OASIS to the extent that it is needed for quality care improvement or to develop a prospective payment system. However, we do oppose any data collection effort that reduces or eliminates the effectiveness of necessary medical services. Accordingly, we urge HCFA to:

1. suspend collection of OASIS data from non-Medicare patients;

2. narrow the OASIS data set down to just the core data that are absolutely essential for the establishment of a case mix adjuster for prospective payment; and

3. collect this narrowed scope of data in a non-identifiable form or in some other manner that does not force patients to choose between necessary health care and their right to medical privacy.

4. reimburse home health agencies for the costs associated with OASIS implementation.

Such an approach should be in the best interest of HCFA as well as the public for the following reasons:

1. it will enhance HCFA's ability to meet the "ambitious" statutory schedule for implementation of prospective payment by October 1, 2000.

2. it will minimize the Y2K computer problems that are likely to arise for HCFA and the health care industry on January 1, 2000.

3. It will give Congress a chance to establish statutory privacy standards which it is required to do by August 21, 1999, and it will minimize the cost and disruption that may occur if OASIS data reporting requirements are inconsistent with the new statutory privacy standards.

Thank you for your interest in working to protect patient privacy and preserve quality care in home health services. I appreciate this opportunity to testify, and I will be happy to answer any questions the committee may have.